

Double or quits: perceptions and management of organ transplantation by adults with cystic fibrosis

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Abstract

Medical sociologists have often considered lay perceptions of the risks of medical interventions, yet in many empirical studies respondents are people who are not likely to be exposed to a particular intervention. Furthermore, it has been well documented that risk perceptions may change over time and with diminishing health state. This paper explores perceptions and management of the risks of organ transplantation amongst adults with cystic fibrosis (CF), the most common autosomal recessive genetic disease in the UK. Although the focus of medical research is now on providing gene replacement therapy to this group, transplantation is currently the last treatment that an adult with CF can be offered when all other treatment has failed to maintain their health. Thirty-one respondents with varying degrees of health state from a specialist CF centre were interviewed as part of a larger study concerning perceptions of health and risks of treatment. Interviews were audiotaped, transcribed and analysed using ATLAS-ti. During analysis respondents' transcripts were divided into two groups: firstly those who did not anticipate needing a transplant in the near future (if at all) and secondly those who were currently being considered for transplantation, on the transplant list, or who had already received donor organs. The paper focuses on themes arising from interview transcripts and finds that although the focus of risk differs between the two groups, the influence of luck is perceived as strong for both groups and emotion work features heavily in those undergoing the transplant process. Contrary to previous research, fears of inheriting donor characteristics are not found amongst adults with CF, but rather body components are commodified when talking of both giving and receiving organs.

Keywords: Organ transplantation, Organ donation, Cystic fibrosis, Health risks, Lay beliefs.

Introduction

Many assessments of the lay public's response to medical technology focus on individuals that have not been exposed to the intervention, or, perhaps more importantly, are unlikely to envisage themselves requiring the technology in the near future. This is despite the observation made over 30 years ago that the general population views a risk situation differently to those who are at risk (Starr, 1969) and the more recent acknowledgement that it is futile to generalise from attitudes of those that are healthy to those whose imminent survival depends on surgery (Radley, 1996).

In the context of organ transplantation, much work surrounds the perceptions of those who are unlikely to require this procedure. For example, in exploring motives for and reactions towards donation and transplantation (Ubel & Loewenstein (1994) and Sanner, 1994 (2001)), how organs should be distributed (Ubel & Loewenstein, 1996) and awareness of transplantation's usefulness and limitations (Calnan & Williams, 1996; Macer, 1993), respondents are members of the general public rather than individuals most likely to require surgery. In these studies ethical and religious dilemmas are raised, for example the removal of the heart for transplantation being perceived as 'sacrilegious' and the essence of a person (Calnan & Williams, 1996). In addition, anthropological studies of life post-transplant raise issues of self-identity and the restructuring of the self once a donor organ is received (see for example Fox, 1996; Sharp, 1995 and Youngner, 1996).

In considering post-transplant outcomes, quality of life (QoL) measures have been used to evaluate the procedure. However 'single shot' questionnaires, which focus on the outcomes of surgery at well-defined timepoints, do not portray the highs and lows of life before and after transplant; accounts of real experiences are needed to add depth to findings (Joralemon &

Fujinaga, 1996) although little qualitative work exists currently on the experiences of recipients (Heyink & Tymstra, 1994 being a notable exception).

This paper presents perceptions and management of the risks of organ transplantation amongst a group of adults with cystic fibrosis (CF) attending a specialist hospital centre in the UK. Here the emphasis is on lung transplantation, as respiratory failure is the most common cause of death for this group (Penketh et al., 1987). Lung or heart–lung transplants (HLT) are performed at a rate of approximately 40 people with CF per year in the UK (McCloskey et al., 1998), this rate hindered only by a general shortage of donor organs (Fisher, Dark, & Corris, 1998; Flume, 1998; Keller, 1998).

CF is the most common autosomal recessive genetic disease in the UK today. The incidence of the disease in the UK has been estimated at 1:2415 births (Dodge et al., 1997). CF is most commonly found in Caucasian populations; a lower occurrence of 1:3500 live births has been described amongst people from Mediterranean countries (Bossi, Battistini, & Braggion, 1999). In the early 1930s 70% of people with CF died before their first birthday (Anderson, 1938); however by 1993 the median survival age was reported to be 27.6 years (FitzSimmons, 1993). Further still, children born in 1990 have been predicted to live for 40 years on average (Elborn, Shale, & Britton, 1991).

The major symptoms of CF arise from abnormal sticky secretions in the respiratory and digestive tracts produced by the ‘CF gene’ identified in 1989 (Rommens et al., 1989); the most common symptom being lung damage from recurring chest infections. The medical focus of potential new treatment is at present on gene replacement therapy (GRT), although adults with CF currently are unlikely to receive this as a licenced treatment. Current routine

treatment for CF is palliative, not curative, and so aims to maintain health by treating the symptoms of the disease as they occur. The mainstays of daily therapies to treat these symptoms over the past three decades have been chest physiotherapy, regular courses of antibiotics and pancreatic enzymes. As health fails, referral for organ transplantation may be offered by the hospital.

Although liver transplants are performed (Scott-Jupp, Lama, & Tammer, 1991), lung and HLT are the most common transplantation procedures for individuals with CF; the first HLTs in these UK patients were performed in 1985 (Scott et al., 1988; Yacoub, Banner, & Khaghani, 1990). Surgeons prefer to perform heart–lung as opposed to lung transplantation as post-operative complications may be less likely in the former (Yacoub et al., 1990). A relatively new procedure is domino transplantation whereby the adult with CF is asked to donate his or her own heart at the time of HLT to an anonymous cardiac recipient (Yacoub et al., 1990), this presenting a rational method of increasing the number of donor organs available. To date, the success rate of this procedure in terms of the heart's function in recipients is very similar to standard heart transplantation (Lowell et al., 2000, Yacoub et al., 1990).

As a group, doctors consider adults with CF to be ideal candidates for organ transplantation, mainly due to their long experience of routine hospital care and treatment (Madden, 1994). The procedure is offered selectively, with specialists at transplant centres advising referral when patients' life expectancy is <2 years or when their condition cannot be stabilised by conventional means (Smyth, Higenbottam, & Scott, 1991). In 1992, the survival rate for adults with CF post HLT was reported to be 49% at 3 years at one London centre (Madden et al., 1992). The survival rate seems to be similar at 5 years to the 3-year rate (Hodson, 1998)

and similar to outcomes reported by other centres (Ryan & Stableforth, 1996) and to recipients with other respiratory conditions (Geddes, 1998b). In reporting long-term survival doctors themselves are surrounded by uncertainty over the long-term effectiveness of organ transplantation (Geddes, 1998b). Furthermore, adults with CF receiving a transplant will continue to ‘suffer’ with CF, for example in experiencing digestive and/or infertility problems, and would have to exchange a daily antibiotic drug regime for a daily immunosuppressive one to prevent rejection of the donor organ (Madden et al. (1992) and Madden et al. (1993)).

It is feasible that people with a shortened natural life span will be prepared to take bigger (or smaller) health risks than those who expect to live into their seventies (Busschbach et al., 1994), however this requires empirical investigation for adults with CF. How do people who are more likely than the general population to need organ transplantation evaluate the risks of the procedure?

Method

The setting and sample

The 31 adults involved in this study all attended a level one specialist CF centre in the UK, which provides national education, training, research and care and treatment of CF, and ranged in age from 18 to 40 years. A list of adult patients living in one geographical area was prepared from the department database, amounting to around 40% of the total number of adults attending the department. Sixteen patients were excluded; one was judged by the staff to be in extremely poor health and one did not speak English as their first language. Fourteen others were excluded because they were siblings of patients who had already been approached

to participate in the study. Organ transplants were performed on 141 adults with CF from this centre between 1985 and 1998, (60% of which were HLT) representing around a quarter of the UK's lung transplants in these adults over that period. Just under half of these were in adults aged 21–30 years.

Letters were sent to 183 clinic patients and 47 patients agreed to participate. Of the 31 who subsequently took part in an interview, 17 were female and 14 were male. Nineteen respondents (61%) had passed the predicted survival age of 27.6 years for this cohort when interviewed (FitzSimmons, 1993). Participants were interviewed in their own homes for between 1 and 1.5 h on average, with the aid of an interview topic guide. Besides exploring respondents' perceptions of organ transplantation, the interview aimed to cover issues such as the health and QoL of those with CF, the perceived risks and benefits of other current and future potential treatments and care, and living with the disease and disclosing the condition to others. Confidentiality was assured for all participants, and assurance given that pseudonyms would be used in any reports. Approval was obtained for this study from the hospital ethics committee.

The analysis

Interviews were tape-recorded and fully transcribed. Transcripts were coded using the ATLAS-ti software programme for qualitative data. Codes were attached to a segment of text such as a word, phrase, sentence or paragraph. These codes were then grouped into categories, providing the conceptual foundations for analysis as described by Dey (1993). The majority of conceptual categories had started to be developed over the course of interviews and were

subsequently developed analytically with conceptual relations being established (Strauss, 1987).

During analysis, interview transcripts from adults with CF were divided into two groups, non-transplant and transplant, to investigate how as a sample their perceptions of the risks of surgery might differ as the possibility of transplantation became a reality. Indeed, the futility of generalisation from one group to another is most pertinent, as adults themselves acknowledged during their interviews that their own ideas concerning the risks of transplantation might change with deteriorating health.

Twenty-three adults formed the non-transplant group; at the time of their interview adults in this group perceived the possibility of needing organ transplantation as remote. The researcher predominantly conceptualised these adults as experiencing a 'normal' level of health, or a health state that was 'controllable' with the routine daily treatment that they were currently taking. Their average age was 30.2 (range 18–40 years, SD 6.3), a similar age to the adults in the second group whose average age was 29.9 (range 21–40 years, SD 7.3), suggesting that age alone has little implication for the necessity for surgery for adults with CF.

Eight adults formed the transplant group; four were post-transplant and included one participant who was on the transplant list for a second time due to chronically rejecting her first donor lung. One adult was on the lung transplant list for the first time and another stated that he had been offered assessment for transplantation by the hospital when he was ready psychologically. Health for the adults who were either currently being considered or waiting for donor organs was mainly conceptualised as 'distressing', as routine treatment failed to stabilise their health.

Key themes surrounding organ transplantation that are addressed here derive from the analysis of respondents' transcripts. Issues covered in the following sections include how health state influences perceptions of transplants, the role of luck, positive attitude and emotion work in a successful outcome and the perception of organs as a 'commodity'. The function of information in considering or undergoing lung transplantation is also explored.

Results

Before perceptions of transplantation are presented, it is prudent to consider briefly how the sample of 31 adults perceived GRT. The majority of respondents did not consider scientific medicine able to create a 'cure' for people currently living with CF. Instead, GRT was seen as the 'cure' that lay ahead for future generations that would benefit from the prevention of lung damage that begins in early childhood, thus negating the need for organ transplantation:

I think it [GRT] will be the cure eventually... I mean I would like to see that in years to come. See, a lot of people say to me, my mother-in-law, for example, she says to me they might find a cure, and like I'm not being pessimistic, I'm not a pessimistic person, I don't think I am, but I say, "No, not for me, but for future [generations]". I'm not as silly to kid myself that I'm going to be cured in ten years' time, but you know if we could look at a day when there doesn't have to be CF, it would be fantastic. (Gill, 30).

It is therefore against the background of transplantation as the last available option to the sample, that the perceptions and management of surgery are considered.

Non-transplant

Emotion work

A 'last ditch attempt' was one phrase used to describe transplantation by the adults in this group. The thought of needing surgery was akin to the idea of reaching the bottom of a 'slippery slope', a period of distressing health before death, which adults reported trying to bracket off from their everyday management of disease through their positive attitude:

I just kind of don't realise that I might need it [an organ transplant], I just think, "Oh no, its' never going to have anything to do with me". I don't like to think of if I did need it because then I'd be quite ill, so I just tend to think I'll be fine, so it's not worth worrying about. (Tessa, 21).

Even adults who were currently experiencing frequent courses of IV antibiotics to control their health expressed doubt that they would come to a point where surgery was necessary, illustrating the positive attitude they continued to hold towards their health:

But I don't ever see myself getting to that point [transplantation]. I just don't see it. (Nicola, 31).

In trying to envisage the prospect of a transplant as perhaps 20 years away, adults suppressed thoughts of future ill health. However, some respondents suggested the possibility of advances in CF management other than GRT. This again was part of the positive way of thinking that adults in this group expressed; that a 'frontier' of scientific medicine would never be reached, as new treatments, such as more powerful antibiotics, would become available making

transplantation less likely. Emotion work, defined as the ‘act of trying to change in degree or quality an evaluation or feeling’ (Hochschild, 1979, p. 561), refers to the effort rather than the outcome of an individual's work. Participants’ effort is evident here in bracketing off or suppressing thoughts of future ill health, and therefore transplantation, through maintaining a positive attitude towards the disease and its future potential treatment.

Luck

People are able to hold two systems of thought on health related topics at the same time (Williams, 1983). Together with a positive attitude, adults in the non-transplant group expressed an overwhelming sense of luck, not just in receiving organs but also in the process and outcome of surgery, making a prediction of personal outcome impossible. Charles was an adult whose health was gradually becoming distressing; he stated he was becoming unable to maintain his level of health on his current treatment of nebulisers and IV antibiotics and spoke about the possibility of undergoing transplantation:

I’d love one [lung transplant] if it worked. If I could get a written guarantee that yes, it would be 100% normal, wouldn’t be any problem whatsoever, then I’d go for it. But do I plod on the way I’m plodding on, which is relatively quite well, I can get about, I can walk, I can drive. Or do I go for a lung transplant and at the end of it I can’t walk and I only live twelve months because of the tablets and the after effects? So, it’s a total gamble, but if you could give me a clad [cast]-iron guarantee... (Charles, 33).

Indeed, four adults in this group made explicit references to transplant surgery holding ‘no guarantees’ of receiving and not rejecting donor organs. Here the science underpinning

transplantation was perceived by respondents as independent and valid; it was the strong influence of chance on the delivery of treatment that was perceived as a risk. Indeed, they noted no correlation between cases of unsuccessful transplant surgery and doctors' personal skills or knowledge but instead stressed the role of chance and its interaction with medical technology.

Although the body is currently available to be 'worked on' by expert systems, here biomedicine, a person's decision to accept high-tech medicine involves the interplay of luck, fate, common sense and conscious risk-taking (Giddens, 1991). In the context of modern medicine risk assessment is 'by definition, imperfect' as it contains so many unknown quantities (Williams & Calnan, 1996). With all transplant surgery there is certainly an element of luck in a successful outcome, despite the obvious scientific progress made (Kahan, 1996), especially in not dying before suitable organs became available (Ryan & Stableforth, 1996).

An improvement to QoL from transplantation was not an overriding notion in this group due to their focus on the role of luck and the uncertainty of outcome inherent in the process. However, adults in the non-transplantation group tended to discuss wider social factors in considering the risks and benefits of transplantation, as opposed to a more narrow focus on their health and emotions during the surgical process. Social areas most commonly considered included home life, partners and actual or potential children; adults stating that these would weigh heavily in their decision to undergo surgery and often contributing to their indecision. Again, references to luck were made:

So unless you're one of the lucky few, the end of your days would be spent in horrendous stressful circumstances. And even when you had the transplant, you could die, 'cause on the medication there's side effects of medication, I understand. But I don't know, I might get there [to the point of needing a transplant] and, say we had a child and the child was three years old, I might think, "Well, even if I only live another five years for the kid, say, it'd be worth it". So I don't know until I'm there, but I think I err on the side of not having one, but I think it's easier to say when you're not at that point. But it's like double or quits, it's either going to be much, much worse or much, much better, you know, and if it's much, much worse I think it's really horrendous. 'Cause that's all you need, you know, waiting list stress, rejection of organ stress, imagine what your partner goes through. (Clare, 35)

Considerable ambivalence surrounds public perception and lay evaluation of science and technology (Giddens, 1991) and Clare's quotation highlights well the ambivalence and uncertainty inherent in transplantation's process and outcome for patients. The majority of the non-transplant group had known adults who had died as a result of transplantation or had had a poor surgical outcome, as well as those who had benefited greatly from the procedure. This added to their indecision of undergoing surgery themselves as Clare's quotation above illustrates; medicine being 'at one and the same time, a fountain of hope and font of despair' (Williams, 1997, p. 1048).

Social role

The notion of organ recipients inheriting parts of the donor's personality or characteristics was not expressed amongst this group despite many other studies of organ transplantation exploring these issues (see for example Doniger, 1996; Fox, 1996; Sharp, 1995; Youngner,

1996). However, some respondents discussed the possibility of HLT changing an individual's social role rather than their self-identity. Emma, a journalist taking nebulisers regularly before and after work, stated that she was given a certain leeway in her employment because of her CF. When imagining herself as having had a successful transplant in the future, the importance of this leeway to her current social role became evident:

You'd probably suddenly have to take on, this is an interesting one, responsibilities [after transplantation]. Now having CF gives you certain leeway like at the moment I turn up late for work, you know. They have a go at me, I say, "Well, look, pal". You know, you bend the rules a bit. And you're able to do that because people do make, you know, sometimes deserved, but occasionally you play it a bit, um, allowances for you. So you would then have absolutely no excuse to do whatever it was, you'd have to go and get on the management scheme, you'd have to go and achieve, you'd have to do this, that and the other.' (Emma, 33)

Although Emma implied that her transplant would have no ill effects and would lead to an excellent QoL, her focus was on a changing social role rather than on inheriting the identity of the donor.

Commodification of organs

The shortage of suitable donor organs means that around half of adults with CF will die on the transplant list (Ryan & Stableforth, 1996; Hodson, 1998). Various ways to reduce the demand: supply ratio (see for example Fisher et al., 1998; Obermann, 1997); have been discussed; moving away from the notion that donation of part of one's body is a 'gift' in the tradition suggested by Titmuss (1970) towards a 'trivialisation and commodification of what is sacred about the human body' (Fox, 1996, pp. 264–265). The 'gift' of a donor organ is said to

create certain obligations; to be an appreciative recipient and to use the gift gratefully (Gerhardt, 1996; Murray, 1996). However conceptions of organ donation as a ‘gift of life’ (Fox, 1996, p. 262) were not stated by any of the adults who were in the non-transplantation group. Indeed, these respondents raised no ethical or moral issues surrounding donors or transplantation. Instead, they were likely to discuss the necessity for more donor organs, for example the need to hold registers whereby people must opt out if they did not wish to donate organs, emphasising the perception of body parts as a commodity:

I think the best answer to the whole thing would be making everyone a compulsory donor, and people being able to opt-out rather than to opt-in. And that I think is what the Government should be looking at, and everyone forcing them to do it. Because at the moment it's [the shortage of donor organs] a ridiculous situation.’ (Mark, 38)

For these adults their own heart was seen as a purely physical commodity in the context of domino transplantation. As one respondent commented on the possibility of donating her heart to another adult when undergoing HLT, ‘why put it in the bin?’ This perception was unlike the healthy lay public's notions of the ‘sacred heart’ being the very core or essence of a person (Calnan & Williams, 1996). Instead, these adults’ focus mirrored their doctors’ view that the CF heart was an organ of secondary importance that had to be replaced in order to have working lungs (Yacoub et al., 1990).

Information

All respondents in the non-transplant group stated that they had not read about the hospital's transplant criteria or procedure, but instead had based their perception of risk on seeing other adults who had undergone transplantation:

She was sitting in the clinic talking to somebody, and I'd overheard what she was talking about. And she'd had a heart and lung transplant. I mean I realised she'd probably got CF 'cause she was sort of floating around in the clinic area, and I thought God, she looks so well. She really did. And I can remember thinking, "God, if that's what it does for you, I'd like one of them." (Catherine, 40)

The amount of information generally about CF that was wanted by patients appeared to change over the course of the illness, regardless of whether or not comparisons were made with others. Some respondents reported actively using ignorance so as not to find out about transplantation until the information became necessary:

But I'm very ignorant. I hardly know anything really. But that's mainly because I don't want to know. (Caroline, 22)

By using ignorance, emotions regarding thoughts of future potential surgery could be managed. However, even adults who did not actively choose to be ignorant of the transplant process stated that hospital staff did not tell them at what stage they would be likely to need a transplant, nor were staff reported to discuss transplants generally until the adults themselves

broached the subject. Therefore adults who reported trying to follow closely information concerning CF acknowledged that transplantation was something that they knew very little about until they were put on the list:

I don't know a lot about transplants. 'Cause it's something that you really don't know a lot about until you're probably put on the list, you know, until they [hospital staff] say to you, "This is it!" (Gill, 30)

Here the specialist centre was thought by respondents to hide the management of the process of dying from the view of those who were not dying imminently. Hospital staff were perceived by respondents to control information more tightly in retaining some aspects of medical information and moving individuals to 'new stages of awareness' (Glaser & Strauss, 1968). Indeed, the lack of knowledge about the medical aspects of transplantation was evident in this group. From their interview transcripts, it was clear that some respondents were not informed about the allocation of organs according to recipients' health state, sizing and tissue matching.

In summary, adults in this group found it difficult to think of a time when organ transplantation might be necessary for them, due to their current health state and positive attitudes towards health. Inherent in accounts were notions of the development of treatments that would make surgery unnecessary, and an overwhelming sense of chance in the outcome of surgery was expressed. Adults did not discuss the possibility of 'inheriting' donor characteristics through transplantation, instead tending to view body organs as a commodity.

Managing the transplant process

In reporting data from adults who were already experiencing the transplantation process it is shown how perceptions of risk change as the possibility of transplantation becomes a reality. The study obviously draws upon adults with non-fatal outcomes of transplantation, although arguably not all are 'successful'.

Eight adults formed the transplant group. One respondent, aged 22, was confined to a wheelchair following the paralysis that occurred during her lung transplantation surgery. Anna, 31, had received a donor liver 9 years prior to her interview. In addition, three adults had undergone HLT (Oscar, 26; Harriet, 34; and Barry, 39). Graham, aged 40, stated that he had been offered assessment for transplantation by the hospital when he was ready psychologically. Tina, 26, was on the transplant list for a second time due to chronically rejecting her first donor lung and a 21-year-old man was on the lung transplant list for the first time.

Emotion work

The medical profession believes that adults must want a transplant for their own benefit as opposed to the benefit of others before they will be considered for surgery (Madden, 1994); that is the wider social considerations expressed by adults in the non-transplant group must be disregarded. However, Graham stated that he was having difficulty conforming to the notion that he should want a transplant purely for himself, stating his concerns for his wife Kay and her son Jeremy:

But I've always said I would love it done for [Kay and Jeremy's] sake. But they [hospital] don't want to do it for [Kay and Jeremy's] sake, they do it for me. (Graham, 40)

Here Graham was being transported from the concept of surgery being a long way off, a notion commonly expressed by respondents in the non-transplant group, towards an imminent reality, and was having to reassess his focus of the risks. Although his quotation below illustrates the ambiguity that was also evident in the non-transplant group, the fear inherent in thinking of potentially imminent surgery is apparent:

KL: How do you feel about HLTs?

Graham: 'Whew! What a question! We [Graham and Kay] talk about this a lot. It frightens me no end to think of someone going in my chest and taking out my heart and lungs and I'm having someone else's. But the idea of being able to breathe and run and possibly, if it all goes well, have a new lease of life, wonderful. If it was as simple as I just said it is... if you asked that question in January, or throughout this year when I've been very, very ill, I'd say to you, "Yeah, great, go ahead and do it"...but it's still pretty frightening. It really frightens me.'

(Graham, 40)

Graham's quotation highlights the possibility of experiencing health as 'a new lease of life' that transplantation offers. However, adults' willingness for surgery can be seen as an 'existential dilemma'—that is the relief of symptoms versus pain and possible death (Radley,

Green, & Radley, 1987). Indeed, the risk of surgery had to be taken, as the only alternative option was certain death:

Death or the transplant. It's a really weird sort of choice really. But that's what it meant, [choosing] between the two. (Barry, 39)

Management of emotion appeared to be the focus for adults throughout the transplant process; for example in managing the distress caused by 'false alarms' when carrying a hospital pager designed to alert patients when donor organs became available. The following quotation is from Barry, who had had a transplant eighteen months prior to his interview. Barry attributed his survival pre-transplant to his refusal to give up, and the emotion work involved in maintaining his body long enough for organs to be found, for example putting himself through 'humiliation' to get treatment; augmenting emotions to achieve certain political gains (Montini, 1996):

And I can honestly remember at one stage actually sort of basically fiddling the system somewhat 'cause I was so exhausted. I was expected to do a physio [chest physiotherapy] and yet I couldn't go to the toilet and back without being totally out of breath, and I just thought, "This is crap." So yes, I put myself under emotional turmoil and did sort of burst into tears at one stage but I did get that physio and that was the whole purpose. And afterwards I thought, 'This is really wrong, to go through this'. [...] I think part of the reason I survived was because I just refused to give up and I would put myself through anything to get the treatment I wanted, including humiliation. And if I had to feel humiliated in order to get the treatment

that I needed, I would do that, ‘cause I wanted to live. I wanted to survive long enough for the transplant. (Barry, 39)

Emotion work can be performed by the self upon others (Hochschild, 1979), here by Barry on the physiotherapists, the ‘moment of “pinch”’ being a discrepancy between what an individual actually does and ought to feel in the given circumstances affected by what an individual thinks he or she ought to feel. Emotion work must deal with concepts of structure (here the hospital) and personality (here Barry's refusal to give up). In ‘fiddling the system’, emotion work became an object of awareness when Barry's feelings did not account for or fit the situation and demonstrates how feelings cannot be measured in the abstract but must be considered within the social situation (Hochschild, 1979). Here Barry was not acting as he thought the hospital expected him to—taking on the role of a passive, compliant patient. Emotion work emphasises overt acts of trying to evoke, manipulate or customise particular emotions and is characterised by a variety of active verb forms (Hochschild, 1979), used here by Barry; ‘I put myself under emotional turmoil’, ‘I just refused to give up’, ‘I would put myself through anything’, ‘if I had to feel humiliated’. In contrast to social considerations such as family and children or even the benefit of improved QoL, the benefit of transplantation for adults waiting for donor organs with extremely distressing health was literally life or death.

Management of surgery

As Radley has suggested of cardiac surgery, those who undertake it never consciously experience the actual surgical operation. It is a paradox; the operation is ‘beyond the horizon

of their consciousness' yet is a 'crucial moment' (1996, p. 118) in that person's life. Despite this 'non-time' however adults described vividly the time directly before and after surgery:

I don't think you really feel that it's happening to you until you actually get on the trolley and you're going through the doors and then by that stage it's too late. Too late to back out then. (Tina, 26)

Other adults with CF who had undergone surgery spoke of the experience of being wheeled into theatre as 'surreal', or as not really happening to them. In saying goodbye to their family, not knowing if they would see them again, management of the actual surgery was akin to the emotional management of death.

Anna stated that days before her liver transplant was performed surgeons had offered her (and she had refused) a 'triple transplant', heart, lungs and liver; this was <2 years after the first ever 'triple' transplant had been announced (Karpf, 1988). In the following quotation Anna contrasts her perception of the lay public's reaction to the transplant process, 'it was so exciting', to her own experience of undergoing high-tech surgery, 'it was a real drag':

And it was so exciting. I got up really early in the morning and had a bath in all this stuff; bits of shaving cream went everywhere. No. It was a real drag. I was so fed up, I couldn't sleep, I was really, really tired. I was just glad to get it over and done with really. And I just remember thinking, "It's got to be better than it is at the moment", you know, "Anything's got to be better". (Anna, 31)

Successful transplants involving individuals with ‘glamorous, dramatic illness’ make excellent ‘good news’ stories (Karpf, 1988) and in reporting transplantation the media focus on the drama and excitement. In contrast, and as the quotations from Barry and Anna illustrate, the route to surgery is painful and far removed from being glamorous.

Adults’ experiences immediately post-operatively were more negatively charged than is regularly reported in the media. For example, being in the intensive care unit (ITU) was reported as an extremely frightening experience. Oscar actually received a donor heart and lungs, although like other respondents he referred only to his ‘new lungs’. He spoke of his experience in the ITU:

First three days [post surgery] I was in such a state, trying to cope with the new lungs, not being able to breathe, and I was so, I was very, very, very frightened. (Oscar, 26)

Routine outcome measures of transplantation such as QoL questionnaires do not pick up the vast range of experiences patients go through in the surgical process (Joralemon & Fujinaga, 1996). As most measure outcome many months or years post surgery, patients’ management of the immediate postoperative period is hidden. Certainly, transplantation did not immediately allay adults’ fears of impending death, whilst recovering in the ITU:

I mean I really thought I was going to die. And there was one time in the intensive care...I remember holding my dad's hand and telling him, “Tell everybody I’m really sorry” ‘cause I

thought I was going [to die] and I'd been a real shit, stupid girl [thinking], "Why can't you get through this one thing?" You know. And I remember that and I thought I was going to die but I couldn't fight it, and I thought, well, up to then I'd done everything that I could have done and I'd done everything I wanted to, and so if this is the time [to die] this is the time, you know.' (Anna, 31)

For Anna and Oscar a fraught period of managing their emotions continued immediately post operatively. However, a smooth immediate post-operative recovery did not prevent adults from managing negative emotions in the longer term. During her interview one recipient described her breakdown 7 years after her transplant. Although counselling had relieved her anxiety, she still admitted to occasional 'blind terrors' that continued to strike without warning:

When I first had my operation I was going fine, I was going great guns and, would you believe, it wasn't until seven years down the line that I had a breakdown. I really did completely hit a wall. And it took seven years [after the transplant], for some reason, to actually sink in. It was like a blind terror. I was in this no man's land. I tell you what brought it on; a really silly thing brought it on. My husband and I were living in a flat and we were happy in that flat, but it came to a point that we decided it was time to move on and look for something else, which is here now. And that was it, I couldn't make that move. I was terrified to move on, to make another beginning. I thought to myself, "I'm not going to see it all nicely decorated." That's when it started, moving on, making new plans, it was like a blind terror, and that's when it suddenly threw me, I didn't know what to do with myself. Half of me was

thinking I was still dependent and ill and the other half was trying to say get on with your life and enjoy it. And I couldn't do the two at the same time. (Harriet, 34)

Harriet's professed anxiety and inability to move forward resembles symptoms displayed by those suffering from post-traumatic stress syndrome and noted in other adults who have had a transplant (Mai, 1986). Before transplantation Harriet considered herself to be a 'dependent' person; at the point of selling her flat Harriet's new role as an individual able to deal with the long-term implications of moving home came to the fore. This is akin to the problem expressed by Emma in the non-transplant group above of leaving one's 'old' social role (of being ill) and acquiring a role as a healthy, capable person, once a successful transplant has taken place.

Although receiving a transplant was also considered to be the 'luck of the draw' by adults in the transplant group, progress made after surgery was attributed not solely to luck or even to medicine, but rather to the emotion work of the recipient. Here a positive attitude was deemed obligatory, especially after surgery when the possibility of rejection became apparent. Indeed, post surgery a good outcome was attributed by these adults as being due more to a positive attitude than to the luck that was a key factor for the non-transplant adults:

There was a young girl who had the operation about a month before me, and she's not with us any longer, but her whole, she moaned from the minute she got it and she never helped herself. [Later] I mean there's lots of us [adults with transplants], I can name quite a few, a handful, that were in the right frame of mind and I really honestly believe that that's how

they've got on, their mental attitude. You've got to be positive, you've got to be, not happy go lucky but you've got to feel, "Well, this is it". You've got to go for it, haven't you?' (Harriet, 34)

Commodification of organs

The 'tyranny of the gift' (Fox, 1996, p. 254), i.e. the obligations perceived by researchers to be inherent in receiving a donor organ, or the work involved in 'repaying a gift' of donor organs (Gerhardt, 1996) were again not identified during analysis of transplant respondents' interviews. Although two of the respondents described organs as a 'gift' in the context of their donation, organs were no longer perceived as a gift when in their body.

The transfer of psychic and social qualities of self that is said to take place following organ transplantation was also not found to be pertinent for this group of adults. Indeed, Anna and Harriet noted having to bracket out thoughts of the donor as a person and to think of body parts in merely physical terms, stating that if they thought about the organ as belonging to a person they 'would go mad'. Certainly in the quotation below it is noted that the donor is depersonalised by references to 'it', not 'he' or 'she':

No, I don't, [think about the personality of the donor] 'cause I think that's rubbish. That person's not in there is it? No, my husband has got two children and just recently they've asked questions, 'cause they're ten and eleven now and they've asked questions and it makes you think and I can honestly say before then I never really gave it a thought, but they asked you questions about the person, "Do you know who the person was?" and, "Do you ever think about the person?" And not till they ask you, like now, do you think about it. But I honestly can say I never ever thought about it. I can't relate to somebody else being in here [chest].

[...] That's how I cope with it. I don't think about this. I mean it's a sad thing to say really but I don't think about that person. (Harriet, 34)

Transplant recipients' denial of the existence of the donor has been interpreted as an 'adaptive function' (Mai, 1986), one that is a powerful and healthy defense mechanism. It could be in this respect that organs become a 'commodity' rather than a gift. A further factor is the amount of emotion work required by recipients, here not thinking about the donor as a person in an attempt to cope with daily life post transplant. Commodification of organs here is not 'profane' (Fox, 1996, p. 262), but rather a practical way of dealing with the transplant process.

In domino transplantation, as for patients with other pulmonary disease (Yacoub et al., 1988), the adult with CF themselves becomes a living donor through donating their heart when receiving both donor heart and lungs. During her interview Tina, on the transplant list for the second time, discussed the option she was given to participate in domino transplantation before her first lung transplant:

Tina: I was on the list for a heart-lung transplant.

KL: Were you? And you got the lungs?

Tina: I just got lungs instead, yeah.

KL: Right. Have you heard of the domino transplant?

Tina: Yeah, I signed the papers for a domino [transplant].

KL: Did you? How did you feel when you thought...?

Tina: I thought that was a brilliant idea. I thought that was really good. 'Cause there's nothing wrong with my heart, it's good.

KL: It's actually a better heart than many people without CF [have].

Tina: Yeah, yeah, So um, yeah, I was quite happy for that, No problem. Quite pleased that it wouldn't be wasted [laughs]. But um, as it turned out, I didn't need to, I kept my own anyway.

In a similar manner to the non-transplant group, Tina referred to the heart as purely a recyclable spare part, 'it wouldn't be wasted', and again the organ can be seen as a commodity rather than a gift.

During his own HLT Barry had donated his own heart to a man with a cardiac condition, Rob, and described subsequently meeting and befriending him in hospital after their operations, a situation similarly described by Sharp (1995). Despite the hospital's attempt to keep the donor details confidential, the two adults' families worked out who the donor and recipient pair were after they had met on the ward, and subsequently told the two men. The donor and recipient are now friends, and although Barry reported initially having problems with his new heart these seemed to be resolved. Barry described his first meeting with the recipient of his heart:

Yeah. I know him, he speaks to me. I ring him up every now and then. We haven't been told officially but it didn't take a lot to work out. [Later] It was a week after the transplant and we were all in the queue for the X-rays, and Rob came. Rob was one row ahead of me and he said, "Ah, by the way, I think I've got your heart". Um, and unfortunately at that stage it was a really bad time because my heart showed signs, it was the only thing I've ever had rejection problems on was my heart. That was the first thing that was going. So I said, "Give it back, you bugger". But I mean, that was a bit pissing-off. (Barry, 39)

Barry's ability to sustain a friendship with the recipient of his heart is perhaps the best testament of how Barry does not regard his heart as a sacred organ or the core of his person, indicating how the heart may become a 'replaceable part' of the body in attempts to manage the disease process. In contrast to the assertion that recipients experience conflict between doctors' objectification of the heart as a 'pump' and wider cultural beliefs (Sharp, 1995), these adults expressed no such reservations.

Information

As previously discussed, adults stated that they received little information from the hospital until they were considered for assessment. At this point sources of hospital information included videos, leaflets and formally meeting other transplant recipients. Adults also compared themselves with others on the transplant list to gauge whether they were indeed suitable candidates for surgery:

I think it was only then that it started dawning on me that I was getting bad 'cause I was looking at people that were going on the list and I'm thinking, 'cause then yes, you do

compare, you were comparing yourself to them, 'cause you're in the hospital so much you are comparing with others. I'm thinking, "Hold on, I'm not much different to them, and they're going for the transplant." Yeah, that was when it started dawning on me. (Oscar, 26)

However, adults who had had a transplant felt that they were no longer 'experts' in CF as they perceived themselves to be to some extent in their routine treatment and care. This was partly because they felt that their respiratory function had improved, or they were no longer suffering from CF at all, so expertise that had been relevant before transplantation was now redundant. Adults also questioned their degree of knowledge of transplants, as information from the specialist centre about life post transplant was perceived to be scarce. Additionally respondents perceived uncertainty in doctors' long-term management of organ transplantation, most commonly with unforeseen problems occurring after transplantation. Respondents' uncertainty centered around the possibility of future organ rejection and was unsettling, as Tina, who was slowly rejecting her donor lungs, noted:

See, that's the thing with having a transplant, I was quite the expert about CF but I'm not about transplants and I don't like the idea that I really don't know. (Tina, 26)

Although information sharing occurred between transplant adults as a group, for example in being asked by the hospital staff to visit others on the list; adults stated that they were conscious of telling others only the positive side of their story, so as not to 'scare' them. However, this effort to maintain a positive attitude also served to reinforce the lack of information about the transplantation process to the non-transplant group. Although Tina stated that she was willing to talk to others awaiting surgery, she was also careful to withhold the unanticipated effects of the process. Here Tina continued her emotion work post-transplant

by ‘surface acting’ (Hochschild, 1983); that is she did not really experience her transplant as unproblematic but worked at giving this impression to others who were themselves waiting to experience the procedure:

I’m also aware, having had a transplant, not to frighten them [others with CF] ‘cause they think, “Oh, that will happen to me” you know, especially now things are going wrong, it can be quite daunting. (Tina, 26)

However, the point was raised by one respondent that it was unfair for those who were ‘lucky’ enough to receive a transplant to give false hope to other adults not yet admitted to the transplant list, but rather that people should be aware that not everyone would do well:

I kind of half feel that it might be like a red rag to a bull because people want to relate to [you]. Yes, I’m an example if you want to see an example of how well a transplant can work, but if you’re suffering and your chances of getting a transplant if you’re not on the list are basically zero, it's kind of defeating. (Barry, 39)

In summary, adults in the transplant group focused overwhelmingly on the emotion work required in the transplantation process. Here emotion work was evident not only in waiting for donor organs to become available, but also in managing the surgery, its outcome, and sharing information with those waiting for organs. Again, commodification of both donor and respondents’ organs was apparent as a practical way of managing the transplant process.

Discussion

This paper has described the perceptions and management of organ transplantation for adults with CF by comparing two groups at extremes of transplantation; those for whom surgery is a distant possibility and those who are heavily involved in its process. By analysing interview material according to respondents' transplant status it has been shown that not only did adults perceive the interventions differently according to their health state, but also that information about transplantation is managed by both the hospital and transplant recipients themselves.

Perceptions of risk change over time and with health state. Here it has been shown that those not experiencing the transplant process gave consideration to the wider-ranging risks and benefits of surgery, paying close attention to the role of chance. However those in the transplant group more firmly grasped the risks of surgery as the only option available to improve health.

QoL questionnaires, used to measure the outcome of transplantation at defined time points, do not portray how individuals manage life before and after transplant. Here, by examining the process together with the outcome of transplantation, it has been shown that risk perception and management change for this patient group as health worsens and further medical intervention becomes likely.

The response rate of 26% in this study was low, although patients were interviewed in order to provide information about the diversity of experience of living with CF and being treated in a specialist clinic for the disease. The findings are likely to generally reflect the views of other adults with CF, as over half of all people with CF are believed to attend some type of specialist CF clinic (CSAG, 1993). More importantly, given that interviewing ended when

new categories or concepts ceased to appear (Burgess, 1982), generalisability might be best judged in terms of logical inference and the plausibility of the analysis (Mitchell, 1983).

Calnan and Williams (1996) recommend inquiry into how far, and in what way, direct experience of a technological procedure and related health problems shapes lay evaluation. Here differences in perceptions within a group of adults with CF have been explored. These adults all attended a specialist CF centre in the UK, which has established links to a transplant centre. This group would have been more likely than other adults with CF to have contact with others who have had a transplant and this may have influenced their perception of the procedure. The difference in risk perception that this might create within one patient group serves to emphasise the range of viewpoints not simply within the lay public in general, but within specific patient groups, according to a complex interaction of factors including health state and style of managing emotionally the effects of the disease.

Like the self, the body can no longer be taken as a fixed physiological entity, but has become deeply involved in our reflexivity (Giddens, 1991). In this study adults did not speak of the heart as a sacred organ, rather that the heart was a 'disposable' organ that had to be transplanted with the lungs to enable more chance of success; here the heart had been commodified (Fox, 1996). Adults with CF are a very medicalised group, used to regular on-going hospital treatment and care (Madden, 1994). This has implications for the reported finding of commodification, as patients' views reflect closely the views of the medical establishment that reinforces objectification and fragmentation of the body into 'parts' (Williams, 1997). However, it is argued here that commodification of organs by these adults is not 'profane' (Fox, 1996), but rather a practical way to experience the transplantation

process. In doing so, it highlights differences in perceptions of medical technology between the lay public and those requiring specific interventions.

Perhaps at odds with the commodification and objectification of body organs is the significant amount of emotion work that adults invest in the transplant process. In divorcing bodily outcomes from the emotional management of treatment in many QoL transplant studies, emotion work is ignored. This is despite the observation by one medical consultant that adults with CF display ‘sheer bloody-mindedness’ in refusing to give up the fight for a donor organ (Geddes, 1998a, p. 999), thus hinting at the prolonged emotion work performed by these patients. This paper has explored emotion work more fully by using data from adults themselves and stresses the work required throughout the whole disease process, from ‘bracketing off’ or suppressing thoughts of future poor health whilst relatively well, to managing emotions many years after transplant surgery.

Luck featured strongly in the majority of respondents’ accounts, regardless of whether they were involved in the transplant process. Although physicians themselves also acknowledge the place of luck in outcomes of transplant surgery, it is not known how health care staff in the CF clinic address this issue. Furthermore, although some patients reported actively using ignorance, information was perceived as scarce until staff raised the possibility of transplantation. Recipients’ own role in restricting information was apparent in serving to maintain others’ positive attitude. This raises the issue of how accurately the transplantation process is portrayed when clinic staff ask recipients to visit other patients on the transplant list.

Overall this paper has attempted to take perceptions of medical technology forward by using respondents from a specific patient group. The analysis is of course based on one-off interviews involving retrospective accounts of the lives of people with CF and reactions to future hypothetical situations. In order to test the ideas presented here of commodification, emotion work and luck, future research needs to concentrate on studying the process of transplantation over time rather than relying on single accounts. A prospective longitudinal study of adults with CF recruited before the need for transplantation arose would be able to examine the issues here amongst people who do not successfully undergo the procedure, and to explore which factors influence changes in risk perception in individual patients.

Main text: 9008

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